

Validation of the Italian version of the Discomfort Scale – Dementia of Alzheimer Type

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Abstract

Title. Validation of the Italian version of the Discomfort Scale – Dementia of Alzheimer Type.

Aim. This paper is a report of a study to validate the Discomfort Scale – Dementia of Alzheimer Type in Italian.

Background. Dementia is a long and highly debilitating illness with a slow course and a steadily rising prevalence. Improving the quality of life of patients with dementia requires instruments to measure their problems and symptoms, because they are unable to communicate and interact with others. In Italy, there are no validated scales to assess discomfort for this population. The Discomfort Scale – Dementia of Alzheimer Type was developed in the USA and has been further tested there as well as in Germany.

Methods. The data were collected by 21 nurses during 2006 in five nursing homes with 71 patients with severe dementia. Face and content validity were evaluated in a focus group. Discriminant validity was assessed with the opposite-group approach and internal consistency and inter-rater reliability were measured.

Results. The discriminant validity of the Italian Discomfort Scale – Dementia of Alzheimer Type showed its ability to detect patients with high and low levels of discomfort. Reliability testing gave positive results: the internal consistency level was satisfactory (0.814) and comparisons of overall discomfort scores across nurses show good reliability.

Conclusion. These findings support the use of Discomfort Scale – Dementia of Alzheimer Type in a clinical setting for people with severe dementia for both research and practice. Its ease of use and comprehensibility, and the limited time required to observe patients renders the Discomfort Scale – Dementia of Alzheimer Type a practical instrument for assessment and choosing care interventions.

Keywords: dementia, Discomfort Scale – Dementia of Alzheimer Type, instrument validation, Italian, long-term facility, nursing

Introduction

Dementia constitutes a health epidemic facing countries around the world. In Italy, the epidemiology of dementia mirrors the worldwide situation. Researchers in the ILSA study (1997) reported a prevalence of 5.3% in males and 7.2% in females aged > 65 years. From 65 to 85 years of age the prevalence of dementia doubles every 5 years, ranging between 42.3% and 63.8% in the population > 95 years (ILSA 1997).

Dementia is a long-lasting, slowly-unfolding, debilitating illness, which leads in the long-term to the need for care, initially provided by informal caregivers. Patients are admitted to long-term care facilities when conditions worsen. In most cases, end-of-life care and treatment are provided at home and in nursing homes (Mitchell *et al.* 2004). In Italy, patients are usually referred to long-term care facilities or nursing homes.

Disease progression leads to increasing loss of cognitive and communicative skills, making it difficult for carers to assess patients' physical and emotional status. A number of instruments for assessing symptoms, specific for people with dementia, are described in the literature (Brugnolli 2007). PAINAID is based on facial expressions and it is the only tool validated in Italian (Costardi *et al.* 2007). However, a symptom or a problem does not necessarily cause pain. The Discomfort Scale – Dementia of Alzheimer Type (DS-DAT) was chosen for validation in Italian because it assesses sensations such as discomfort during an episode of fever, which is different from a painful condition although still disturbing for the patient.

The DS-DAT is based on non-verbal communication and so is particularly suitable for these patients (Hurley *et al.* 1992). Discomfort is defined as behaviour indicating a negative emotional and/or physical status that can be identified by a trained observer unfamiliar with the patient's usual behavioural pattern (Hurley *et al.* 1992).

Discomfort Scale – Dementia of Alzheimer Type

The Discomfort Scale – Dementia of Alzheimer Type is based on two assumptions: people with severe dementia can express their discomfort similarly to infants and children by non-verbal communication, using facial expressions, body language, gesture, posture, voice tones or vocalizations; thus discomfort can be identified, even if it is not verbally expressed.

The DS-DAT includes nine indicators (noisy breathing, negative vocalization, sad facial expression, frightened facial expression, frown, tense body language, fidgeting, content

facial expression and relaxed body language). They are recorded over a 5-minute observation period and scored for frequency, intensity and duration from 0 (no discomfort) to 27 (maximum discomfort).

Each item is measured for frequency (number of episodes during 5 minutes) and may achieve a score from 0 to 3, intensity (low: barely to moderately perceptible; high: present in moderate to great magnitude) and duration (short: shorter than a minute; long: a minute or more); this rating gives a total score from 0 (no discomfort) to 27 (high level of discomfort). An item that cannot be observed scores 0.

The scale was designed and tested in the United States of America in three consecutive studies (Hurley *et al.* 1992) in nine long-term care and five medical units. Cronbach's α ranged from 0.86 to 0.89. Inter-rater and test-retest reliability was evaluated using Pearson's r and the paired t -test; inter-rater reliability gave r between 0.86 and 0.98, paired t -test scores ranged from 0.06 to 1.6, and were low and non-statistically significant. Test-retest reliability was examined: 68 residents were scored twice at 1-hour intervals by two independent raters: Pearson's r was 0.60 ($P < 0.001$), and the paired t -test gave 0.70 ($P > 0.05$). These results support the use of the DS-DAT for assessing discomfort in clinical settings in patients with dementia (Hurley *et al.* 1992).

Additional psychometric evaluations of the DS-DAT were performed by Miller *et al.* (1996) in two acute care medical units and by Young (2001) in a long-term care unit. The DS-DAT was used in the acute care setting (Miller *et al.* 1996) with a sample of 46 older people, with inter-rater reliability being measured at two time points in 32 pairs of observations. Pearson's r was 0.67 and good results were reported for reliability. Young (2001) used it in a long-term care setting with a sample of 104 residents, confirmed its good internal consistency (Cronbach's α 0.74), and inter-rater reliability was 84% after 30 hours of training and 94% after 5 hours of additional training.

German researchers validated the scale with 662 patients with pneumonia and dementia, confirming the good performance of the instrument: Cronbach's α ranged between 0.82 and 0.84 (van der Steen *et al.* 2002). Pasman *et al.* (2005) also assessed the level of discomfort in 178 patients in long-term care facilities after artificial nutrition and hydration had been interrupted. There was a progressive decrease of discomfort, illustrating discriminant validity.

The study

Aim

The aim of this study is to validate the DS-DAT in Italian.

Methods

Language and content validation

The DS-DAT was independently translated from English to Italian by a physician and a nurse with good knowledge of English. The translations were compared and harmonized by a supervisor. Back-translation was performed by a nurse whose mother tongue was English and by a professional scientific translator, and again the supervisor evaluated the equivalence of the translations with the original scale and if necessary modified the Italian version. The aim of this study is to obtain an accurate, easily-understood instrument, consistent with the original but adapted to the Italian context.

Face and content validity were assessed by a group of five nurses and four physicians with at least 1 year of experience in the care of people with dementia. They suggested no major changes.

The final pilot test was carried out in one nursing home in Turin, Italy. Four expert nurses (at least 1 year of experience) tested 16 patients, whose Functional Assessing Staging (FAST) score was stage >7 (Reisberg 1988), to assess ease of use and clarity of the Italian version of the DS-DAT to identify any ambiguous items and suggest clarifications. The FAST scale is a test of functioning tailored for Alzheimer's disease; it consists of seven major stages with a total of 16 stages and sub-stages from 1 to 7 (stage 7 indicates the most advanced dementia and is divided as follows: 7a, speech limited to 1–5 words; 7b, loss of all intelligible vocabulary; 7c, no walking; 7d, unable to sit independently; 7e, unable to smile; 7f, unable to hold head up).

Discriminant validity and reliability assessment

Discriminant validity and reliability were assessed in five nursing homes in 2006. Each patient was independently assessed by two nurses: the first evaluated the discomfort level (low/high) according to their clinical judgement and then with the DS-DAT. The second nurse, blind to the first nurse's judgement, assessed the patient with the DS-DAT scale within 1 hour of the first assessment. The patient was assessed during the shift change, when the two nurses were both present, and assessments took from 7 to 10 minutes.

Discriminant validity was measured following the contrasting-group approach. Patients with higher levels of discomfort were expected to obtain lower scores. Reliability was measured on the basis of inter-rater reliability and internal consistency. Reliability refers to the ability of the scale to provide constant results when used repeatedly with the same population (Higginson & Carr 2001), while internal consistency indicates the coherence among items in the same scale. Data were collected for the analysis of

reliability in parallel with the test for discriminant validity. All patients were independently assessed by two expert nurses.

Nurses were invited to try out the scale with at least two patients before starting data collection, to become familiar with it. For this purpose they observed patients for 5 minutes.

Ethical considerations

Patient care was not affected by the study and any additional information collected was already part of routine care. Data were presented without any reference to individual patients or nursing homes, and so approval from the institution was deemed to be sufficient and patients' relatives were not asked for authorization.

Data analysis

Discomfort scores are reported as means and standard deviations. Discriminant validity was assessed by testing the differences between the two patient groups (high and low discomfort) on mean values for all nine items using the Kruskal–Wallis test. A *t*-test for independent data was applied to test the difference on the total discomfort score obtained by summing the nine items.

Inter-rater reliability was estimated by calculating Cohen's Kappa index for single items and intra-class correlation coefficient for the total discomfort score. Strength of agreement between the two different evaluators was assessed as low (agreement index < 0.2), fair (0.21–0.40), moderate (0.41–0.6), substantial (0.61–0.8) and almost perfect (0.81–1.00).

The internal consistency of the total discomfort score was measured by Cronbach's alpha; coefficient values higher than 0.80 indicate a good internal consistency. Statistical analyses were performed with STATA Statistical Software, Release 10 (Stata Corp, College Station, TX, USA).

Results

Language and content validation

Overall, the DS-DAT translation was satisfactory and the original content was almost unaltered, requiring only a few changes. The phrase 'absence of' was added to items 'content facial expression' and 'relaxed body language' because all the other indicators identified negative behaviours.

The instructions for administering the DS-DAT were modified as follows

Table 1 Discriminant validity: comparison of low and high discomfort groups

Indicator	Low discomfort <i>n</i> = 44 (mean ± SD)	High discomfort <i>n</i> = 27 (mean ± SD)	<i>P</i> value*
1. Noisy breathing	0.32 ± 0.83	0.74 ± 1.20	0.0812
2. Negative vocalizations	0.68 ± 1.18	1.85 ± 1.35	0.0019
3. Lack of content facial expression	1.11 ± 1.33	2.33 ± 1.14	0.0004
4. Sad facial expression	1.14 ± 1.36	2.11 ± 1.19	0.0023
5. Frightened facial expression	0.93 ± 1.25	1.67 ± 1.41	0.0379
6. Frown	0.72 ± 1.08	2.19 ± 1.24	0.0001
7. Lack of relaxed body language	1.09 ± 1.38	2.30 ± 1.20	0.0008
8. Tense body language	1.00 ± 1.31	2.48 ± 1.05	0.0001
9. Fidgeting	0.84 ± 1.31	1.93 ± 1.38	0.0016

*Kruskal–Wallis test.

- When ‘frequency’ of behavioural indicators is scored 0 (for instance, absence of noisy breathing), the same score must also be entered in the ‘intensity’ and ‘duration’ boxes.
- When behavioural indicators show up constantly (for instance, the patient produces negative vocalizations for the entire 5-minute observation), the score for ‘frequency’ is ≥ 3 (≥ 3 episodes), while the score in the ‘duration’ box must be given as ‘long’ (≥ 1 minute).
- During observation, external interference (someone entering the room, coming close to the patient, opening windows, shutting the door, changing the bed inclination, calling the patient loudly, etc.) must be kept to a minimum.
- One characteristic of discomfort is sufficient for the corresponding indicator to be considered positive.

Discriminant validity and reliability

Scores for individual indicators in the two groups of patients are shown in Table 1. Differences between patients clinically classified at high and low levels of discomfort were statistically significant ($P < 0.05$) for all indicators except *noisy breathing*.

After the initial assessment, 71 patients (53 women and 18 men, mean age 81.4 years) were divided into two groups of 44 and 27, with low and high levels of discomfort respectively; further details are set out in Table 2. In all, 17 nurses and four nursing coordinators experienced in the care of people with dementia assessed the patients.

The difference between total mean scores was statistically significant ($P < 0.0001$). Patients with a low level of discomfort obtained a median score of 6 (range 4–11) as compared with 19 (range 15–22) in the high-discomfort group, thus confirming the discriminant validity of the Italian version of the DS-DAT.

Internal consistency measured by Cronbach’s α was 0.814 (Table 3). Item-test correlations ranged between 0.428 and

Table 2 Characteristics of patients (*n* = 71)

Age (years)	81.48 ± 7.64 (76–86)*
Males (%)	18 (25.4)
Females (%)	53 (74.6)
FAST stage [†] , <i>n</i> (%)	
7a	13 (18.3)
7b	12 (16.9)
7c	17 (24)
7d	12 (17)
7e	14 (19.3)
7f	3 (4.2)
Level of discomfort, <i>n</i> (%)	
Low	44 (62)
High	27 (38)

*Mean ± SD (1st and 3rd quartiles).

[†]FAST, Functional Assessing Staging. Stage 7 indicates the most advanced dementia and is divided as follows: 7a, speech limited to 1–5 words; 7b, loss of all intelligible vocabulary; 7c, no walking; 7d, unable to sit independently; 7e, unable to smile; 7f, unable to hold head up.

Table 3 Internal consistency: item rest-correlation and Cronbach’s alpha for each indicator and for the total mean

Indicator	Item rest-correlation (<i>n</i> = 71)	Cronbach’s α (<i>n</i> = 71)
1. Noisy breathing	0.428	0.805
2. Negative vocalizations	0.444	0.803
3. Lack of content facial expression	0.582	0.787
4. Sad facial expression	0.454	0.802
5. Frightened facial expression	0.459	0.801
6. Frown	0.677	0.774
7. Lack of relaxed body language	0.627	0.780
8. Tense body language	0.607	0.783
9. Fidgeting	0.327	0.817
Mean (standardized items)		0.814

What is already known about this topic

- Assessing discomfort and measuring problems and symptoms of patients who are unable to communicate and interact with others is difficult.
- No valid and reliable instruments for assessing discomfort are available in Italian.
- The lack of valid and reliable instruments makes it difficult to compare assessments between nurses.

What this paper adds

- Nurses can assess the discomfort of people with dementia in Italian long-term care settings with this valid and reliable instrument.
- The DS-DAT can be easily used in routine care.
- Structured observation of patients' behaviours provides a reliable basis for distinguishing high and low levels of discomfort.

Table 4 Reproducibility: concordance for single indicators and for the total mean discomfort scores

Indicator	Agreement index (95% CI)
1. Noisy breathing	0.803 (0.396–0.916)*
2. Negative vocalizations	0.851 (0.779–0.960)*
3. Lack of content facial expression	0.732 (0.542–0.871)*
4. Sad facial expression	0.653 (0.497–0.821)*
5. Frightened facial expression	0.673 (0.482–0.829)*
6. Frown	0.630 (0.455–0.817)*
7. Lack of relaxed body language	0.755 (0.619–0.894)*
8. Tense body language	0.668 (0.528–0.784)*
9. Fidgeting	0.685 (0.587–0.850)*
Total mean discomfort score	0.846 (0.779–0.912) [†]

*Cohen's Kappa.

[†]Intra-class correlation coefficient.

0.677, with the exception of the item *fidgeting* (0.327), thus indicating a good behaviour and correlation of indicators.

The mean interval between assessments was 15 (5–25) minutes. Agreement indices for single items and total mean discomfort scores are shown in Table 4. Inter-rater reliability was almost perfect for *noisy breathing*, *negative vocalizations* and *lack of content facial expression* and for the total discomfort score, and was good for the other items.

Discussion

The results showed that the Italian version of the DS-DAT is a valid and reliable instrument for evaluating discomfort in people with severe dementia.

In agreement with previous reports (Hurley *et al.* 1992, Miller *et al.* 1996, van der Steen *et al.* 2002) our findings indicate good internal consistency of the DS-DAT Italian version. Cronbach's α (0.814) was good, as in the studies by Hurley *et al.* (1992) (0.86–0.89) and van der Steen *et al.* (2002) and higher than the 0.74 reported by Young (2001). The item-test correlation proved satisfactory, with the sole exception of the indicator *fidgeting*, implying that all indicators measured the same underlying concept. Cronbach's alpha, excluding *fidgeting*, was 0.817, very close to the alpha of 0.814; therefore, as the scale has already been validated and the concept of *fidgeting* is well known, the item was considered reliable.

The DS-DAT Italian version also showed very good inter-rater reliability. The intra-class correlation coefficient for the total discomfort score (0.846) was higher than the 0.50 reported by van der Steen *et al.* (2003). This difference is likely to be as a result of the fact that the nurses carrying out the assessments worked in the ward and therefore were aware of their patients' clinical course and could share views on their discomfort.

Several issues still require attention. The Italian version of the DS-DAT was validated in long-term care units, not in acute care settings as in the Miller *et al.* (1996) study. Further research is needed to adapt the scale to acute care settings, considering the specific features such as shorter time to become acquainted with patients and greater disturbance in the surroundings.

Our set of patients included over 70% of women, in line with the prevalence of dementia in the Italian population according to the ILSA study (1997). However, we found no data in the literature on differences in physical attitudes, behaviours and emotions between male and female patients.

Valid and reliable tools to measure symptoms and behaviour in patients with cognitive deficits are useful in research and clinical practice because pain and other symptoms are often underestimated (Mitchell *et al.* 2004). The measurement of quality of life and level of discomfort becomes more complex as the illness progresses. In the end-stage, patients with dementia show increasing difficulties in interacting with others. Simple and easy-to-use instruments to assess their condition in clinical practice are very helpful in understanding patients' reactions.

Conclusion

The DS-DAT is a ready-to-use, easy-to-administer, effective instrument for healthcare workers in long-term care facilities, including staff who regularly interact with patients and

therefore need instruments to reliably assess their comfort and wellbeing. The instrument could also be useful in other patients with cognitive or communication difficulties to help assess the effectiveness of symptom control, improve pain control and minimize the variability of assessments. This validated Italian version is therefore useful for clinical practice and research.

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Author contributions

CDR, PDG, CB, VD & FT were responsible for the study conception and design. CDR performed the data collection. CDR, PDG & CB performed the data analysis. CDR & PDG were responsible for the drafting of the manuscript. CDR, PDG, CD, VD, DV & FT made critical revisions to the paper for important intellectual content. CB provided statistical expertise. FT obtained funding. CB, VD & FT supervised the study.

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